

From the Canadian Paediatric Society

Treatment decisions for infants and children

Bioethics Committee,* Canadian Paediatric Society

Treatment of critically ill newborns or older children who have serious handicaps has always been a matter of extreme concern for physicians and parents. Increasingly frequent interventions, comments and criticism from various sources outside the health care profession have added new facets to what was at one time a very personal and private dilemma.

The primary concern of physicians caring for children must be the best interests of the child. All infants and children have intrinsic value and deserve our respect and protection. This is true regardless of whether they are handicapped or have the potential to be handicapped and of whether the handicap is physical or mental. This means that *all* children have a justified claim to life and therefore to such medical treatment as is necessary to either improve or prolong life.

The capacity of modern medicine and technology to prolong life is now so advanced that there is a real danger that the prolongation of life will become the sole end, irrespective of the havoc it may wreak on other persons or desirable goals. The decision to use life-prolonging treatment must be guided by the best interests of the child.

The best interests of the child can be defined as the balance of potential benefit over potential harm or distress resulting from the pursuit of a given line of treatment. No other interest can override those of the child, whether it be family stability or well-being or the well-being of other providers of care. Although the burdens placed on

the family must be considered when decisions are made, neither these burdens nor those placed on health care professionals or the community can be the primary reason for withholding treatment. Careful consideration must be given to all possible identifiable outcomes (beneficial and harmful) of *both* treatment and nontreatment.

Usually the best interests of the child will favour the provision of life-sustaining treatment. This is evident when the result of treatment will be survival of the child with no or little handicap but should be equally true even when a chronic physical or mental handicap will continue to be present.

A primary role of medicine is to maintain life but not to unthinkingly prolong the dying process. Thus, under the following circumstances there are exceptions to the general duty of providing life-sustaining or life-prolonging treatment.

- When there is irreversible progression of disease, and death is imminent.
- When treatment will clearly be ineffective or harmful.
- When life will be severely shortened regardless of treatment and when nontreatment will allow a greater degree of caring and comfort.
- When the patient's life will be filled with intolerable and intractable pain and suffering.

If selective nontreatment is chosen the subsequent management of the child and family should be carried out with the utmost sensitivity, support and compassion. Under these circumstances care of the child includes the provision of warmth and physical and social comfort, enteric feeding (when biologically possible), hydration and control of pain, even when the use of analgesics may conceivably hasten death. However, the use of sedatives or analgesics with the object of hastening death is forbidden, as is the use of sedatives to achieve persistent sleep.

There remain conditions in which the best interests of the child are uncertain because of difficulty in determining either the likely outcome or whether the outcome can be considered beneficial or harmful. The presupposition in these circumstances should be in favour of life-saving or life-sustaining treatment. However, when possible,

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acute treatment measures should be delayed while certain procedures for decision-making, described below, are followed.

Parents have a moral and legal responsibility for the well-being of their children and, therefore, should be the surrogates for providing consent unless they are incompetent to make decisions, there are unresolvable differences between them or they have clearly relinquished responsibility for the child. In the last case a legal guardian should be appointed before any decisions regarding withholding treatment are made. If the parents are separated, the one who is the legal guardian is responsible for providing consent.

When it is clear that treatment is in the child's best interests it is the physician's responsibility to ensure that the parents understand this. Refusal by the parents to permit such treatment requires the intervention of the court. When it is judged after discussion between the physician and the parents that the child's best interests are clearly not met by a particular treatment no further formal support for a decision to withhold that treatment is required. However, all decisions to withhold or withdraw treatment should be followed by an ethical review.

When the best interests of the child are uncertain, treatment should generally continue. A second opinion from an appropriate consultant is mandatory. When there is disagreement either between the parents and the physician or among health care professionals, it is strongly recom-

mended that the dilemma be presented to an institutionally approved group such as an ethics advisory committee. The primary roles of such a committee are to clarify ethical issues, both substantive and procedural, and to assist parents and health care professionals in coming to conclusions that are mutually and societally acceptable.

Selected reading

- American Academy of Pediatrics Infant Bioethics Task Force and Consultants: Guidelines for infant bioethics committees. *Pediatrics* 1984; 74: 306-310
- Campbell AGM, Duff RS: Deciding the care of severely malformed or dying infants. *J Med Ethics* 1979; 5: 65-67
- Fleischman AR, Murray TH: Ethics committees for Infants Doe? *Hastings Cent Rep* 1983; 13: 5-9
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- Ramsey P: *Ethics at the Edge of Life: Medical and Legal Intersections*, Yale U Pr, New Haven, Conn, 1978
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Sept. 28-Oct. 1, 1986

Sixth International Seminar on Terminal Care
Montreal
Dr. Balfour M. Mount, director, Palliative Care Service,
Royal Victoria Hospital, 687 Pine Ave. W, Montreal,
PQ H3A 1A1; (514) 842-0863

October

Oct. 3, 1986

University of Western Ontario Research Day in Family
Medicine
Park Lane Hotel, London
Dr. J.F. Sangster, 1228 Commissioners Rd. W, London,
Ont. N6K 1C7

Oct. 5-8, 1986

Physician Manager Institute 1986: the Foundations of
Management
Deerhurst Inn & Country Club, Huntsville, Ont.

Mr. Chuck Shields, Canadian College of Health Service
Executives, 201-17 York St., Ottawa, Ont. K1N 5S7;
(613) 235-7218 or Mr. Joe Chouinard, Canadian
Medical Association, 1867 Alta Vista Dr., Ottawa,
Ont. K1G 3Y6; (613) 731-9331

November

Nov. 2-6, 1986

15th Annual Educational & Scientific Meeting of the
Canadian Association on Gerontology
Quebec Hilton International, Quebec City
Canadian Association on Gerontology, 238 Portage
Ave., 2nd Floor, Winnipeg, Man. R3C 0B1; (204)
944-9158

Nov. 6, 1986

Computers in Medical Education
Mount Sinai Hospital, Toronto
Continuing Medical Education, University of Toronto,
116-150 College St., Toronto, Ont. M5S 1A8;
(416) 978-2718

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